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# ENVIRONMENTAL PUBLIC HEALTH TRACKING<sup>1</sup>

## AN INITIAL ANALYSIS OF ENVIRONMENTAL PUBLIC HEALTH TRACKING STATUTES AND REGULATIONS AND THE MONTANA CODE AND ADMINISTRATIVE RULES

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This document provides a systematic and thorough analysis of the state statutes and regulations related to the national Environmental Public Health Tracking (EPHT) initiative advanced by the Centers for Disease Control and Prevention (CDC). In addition, this document compares these statutes and regulations with the Montana state code (MT Code) and the Administrative Rules of Montana (ARM) and identifies several areas where model EPHT statutes and regulations [to be developed] could be incorporated into Montana's existing legal infrastructure. This analysis will present an initial assessment of the compatibility of the MT Code and ARM with the goals of EPHT, and will serve as a foundation for the drafting of model EPHT language for the state of Montana that can be incorporated in Montana's public health law modernization process.

The analysis in this report builds on the previous efforts by Lawrence O. Gostin and James G. Hodge, Jr., to analyze the MT Code and ARM as they relate to the provisions of the Turning Point Model State Public Health Act (MSPHA).<sup>2</sup> Whereas the purpose of the prior analysis was to identify potential gaps in the MT Code and ARM pertaining to public health law generally, the current report expands the focus to assess whether the laws and regulations in the state of Montana support EPHT.<sup>3</sup> While some sections of MT state laws could facilitate EPHT activities in their current form, the final section of the report offers some initial legal recommendations to foster more direct implementation of EPHT. These recommendations will be developed further through a

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<sup>2</sup> See <http://www.publichealthlaw.net/Resources/Modellaws.htm> for a complete copy.

<sup>3</sup> Information regarding the MT Code and the ARM, as well as the statutory and regulatory provisions from other states, were gathered from the legal search engines Lexis and Westlaw as well as the website of the state of Montana.

series of subsequent analyses to be produced during the coming year in collaboration with our partners at the Montana DPHHS.

## **I. Overview of EPHT**

The concept of EPHT is rooted in efforts to assess the effects of exposures to environmental hazards on public health outcomes. While substantial evidence of this linkage exists, efforts to establish the relationship between environmental factors and health effects, and to carefully develop prevention and intervention strategies to reduce the health risks of environmental exposures, have been lacking. Public health surveillance data have not been systematically utilized, together with environmental hazard data and exposure monitoring data, in an integrated effort to track the associations between environmental factors and health outcomes.<sup>4</sup>

In 2002, Congress authorized the CDC to begin funding EPHT programs in several states to cultivate the study of correlations between environment factors and non-infectious diseases. The predominant goal of CDC's national EPHT program is to establish a national network that will enable the ongoing collection, integration, analysis, and interpretation of data about environmental hazards, exposure to environmental hazards, and health effects potentially related to exposure to environmental hazards.<sup>5</sup> Multiple efforts to develop a national EPHT system are now underway.<sup>6</sup>

Early on in this program, it became evident that many states had not yet assessed their state laws to determine whether they had sufficient legal authority to engage in all of the activities necessary for a robust EPHT program. The state of Montana has taken a proactive approach in evaluating its state laws relevant to EPHT. The sections that follow 1) outline the major legal issues that may affect the development, implementation, and operation of EPHT at the state level, 2) describe the general findings of our assessment of state laws related to EPHT, 3) present an evaluation of the statutory and regulatory infrastructure of the state of Montana related to EPHT; and 4) offer some preliminary recommendations.

Generally, Montana possesses some of the legal authorities necessary to acquire and utilize data for EPHT. However, the development and implementation of an effective EPHT system will require modification of the legal infrastructure and likely necessitate additional legal powers related to data collection and sharing.

## **II. Legal Powers, Authorities, and Barriers to EPHT**

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<sup>4</sup> Pew Environmental Health Commission, *America's Environmental Health Gap: Why the Country Needs a Nationwide Health Tracking Network*, September 2000.

<sup>5</sup> Centers for Disease Control and Prevention, *CDC's Strategy for the National Environmental Public Health Tracking Program, Fiscal Years 2005-2010* (2005).

<sup>6</sup> Michael A. McGeehin, Judith R. Qualters, Amanda Sue Niskar, *National Environmental Public Health Tracking Program: Bridging the Information Gap*, 112 (14) ENVIRON. HEALTH PERSPECTIVES 1409 (October 2004).

A successful EPHT program demands a robust information infrastructure to track relevant environmental factors and analyze their impact on population health. State statutes and regulations are key to the development of this information infrastructure. State laws may authorize or limit the ability of state agencies to acquire, use, retain, or disclose data on environmental hazards, environmental exposures, and health human effects. Consequently, statutes and regulations have a fundamental role in the ability of Montana, or any state, to effectively implement an EPHT system.

The major legal issues related to EPHT may be categorized as follows:

**Statutes or regulations that facilitate the acquisition of data.** Several types of statutes or regulations may facilitate the acquisition of the three categories of data—environmental hazards, environmental exposures, public health indicators—integral to EPHT. These include legal provisions that:

- authorize the collection of relevant health and environmental data by government agencies;
- require individuals or entities to report specific information to these agencies;
- allow agencies themselves to access existing databases containing germane information; and
- protect privacy of individuals and groups consistent with the public health objectives.

Within each category, statutes and regulations may or may not allow for the acquisition of specific data (i.e., data related to a specific environmental hazard, environmental exposure, or public health condition). To fully implement EPHT, government agencies may need additional authority to acquire needed information.

**Statutes or regulations that allow or restrict the use of data for EPHT efforts.**

**Legal authority to use data for EPHT.** Once data are acquired by a government agency, law may dictate whether these data can be used to engage in EPHT activities.

- Efforts to compare environmental hazard data, environmental exposure data, and public health data may be complicated if statutes and regulations do not authorize sharing data between more than one government agency.
- The evaluation and analysis of EPHT data may require additional follow-up investigations in the potentially affected populations to establish a causal link between environmental exposures and health effects. Therefore, whether the law permits data to be used for proactive epidemiological studies could significantly impact the scope of the EPHT program. Relatedly, law may determine the availability of these data for additional public health activities outside of tracking, including public

health research, partner notification, direct health care and treatment, resource allocation review, and general public health policymaking.

- The law may or may not allow data to be disclosed outside of the state government agency that collected it for purposes of EPHT, for example, to the federal government or private researchers.

Many state laws do not directly focus on the issue of subsequent uses and disclosures of data whether to entities within or outside of the government agency that has the data. The more clearly these issues are addressed in statutory or regulatory language, the more likely the state will be able to engage in EPHT.

**Restrictions on the use of data for EPHT.** Many laws at the federal and state levels provide substantial privacy and confidentiality protections for information collected and retained by state agencies or other participants in the health system.<sup>7</sup> The justifications for these protections may stem from several sources.

- Laws frequently place strong privacy protections on identifiable health and medical data. Federal and state information privacy laws may restrict the use or disclosure of data without consent, or may impose difficult prerequisites to information sharing that hinder EPHT efforts. Access to and disclosure of data is often limited due to the desire to afford individuals the right to determine who has access to potentially sensitive and private information about them.
- Laws also often protect the confidentiality of environmental hazard reports that may contain proprietary business information, such as trade secrets.

Respecting these privacy and proprietary concerns encourages individuals, health professionals, and corporations to continue to cooperate with reporting requirements and requests for information vital to a functioning EPHT system. However, efforts to maintain good data stewardship should not be a barrier to EPHT. The relevant statutes and regulations may need to be reformed to balance these concerns.

### **III. Assessment of State Legal Provisions Relevant to EPHT**

In order to identify how states have addressed the prevailing legal issues attendant to EPHT, we reviewed statutes and regulations from states around the country. We also analyzed relevant federal laws such as the Privacy Regulations promulgated under the Health Insurance Portability and Accountability Act of 1996 (HIPAA Privacy Rule).<sup>8</sup> Our assessment of state statutes and regulations uncovered very few states that have directly considered or enacted discrete legislation to create an EPHT program. Likewise, most

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<sup>7</sup> Health information privacy laws typically only apply to identifiable information. Non-identifiable information does not raise the same privacy concerns, unless there are group privacy concerns about the release of aggregated, non-identifiable data. *See, e.g.,* Lawrence O. Gostin, *Health Information Privacy*, 80 CORNELL L. REV. 451 (1995).

<sup>8</sup> 45 CFR §§ 160, 164 (2002).

states have not yet explicitly attempted to incorporate EPHT into their existing state legal frameworks. Nevertheless, many existing state legal provisions authorize data collection and sharing activities that would be integral to and necessary for an EPHT initiative.

**EPHT-specific state laws.** The state of California has the most advanced state EPHT program in the country, having implemented EPHT legislation in 2001<sup>9</sup> and again in 2003.<sup>10</sup> Since the passage of this legislation, California has made great progress in the development of their EPHT program, authorizing a working group: 1) to formulate enhanced surveillance systems for environmental and health data; 2) to cultivate greater coordination between agencies and databases; and 3) to suggest how EPHT data could be shared with the community.<sup>11</sup> Nevertheless, California's Environmental Health Surveillance System (EHSS) is still in development. While several pilot studies are underway to demonstrate the feasibility of utilizing existing data to improve public health knowledge while maintaining data confidentiality,<sup>12</sup> further legislative efforts to centralize the EHSS in a centralized "Office of Tracking" have yet to succeed.<sup>13</sup>

Several other states, including Florida,<sup>14</sup> Louisiana,<sup>15</sup> and Montana,<sup>16</sup> have statutorily created committees to study the possibility of implementing EPHT systems, but these states have not yet taken further legislative steps to develop an operational EPHT system.

**EPHT under existing state laws.** Due to the relative paucity of state legislation directly authorizing EPHT initiatives, we further examined existing state statutes and regulations that would affect the development and implementation of EPHT. We assessed the application of existing state laws related to the acquisition, use, and disclosure of data relevant to EPHT, as well as federal and state laws protecting information privacy. This review included statutes and regulations establishing public health powers, environmental

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<sup>9</sup> California Senate Bill 702 (Escutia, 2001).

<sup>10</sup> California Health Tracking Act of 2003, California Senate Bill 189 (Escutia, 2003).

<sup>11</sup> Between 2001 and 2004, the California Policy Research Center, pursuant to a request from the California legislature, prepared a strategy for the state to adopt and implement an Environmental Public Health Tracking (EPHT) system. See California Research Policy Center, *Strategies for Establishing an Environmental Health Surveillance System in California: A Report of the SB 702 Expert Working Group* (2004). The California Environmental Health Tracking System has created a useful website, available at <http://www.catracking.com/>.

<sup>12</sup> The Almeida County Pilot Program is tracking asthma outcomes through the use of several existing datasets. See <http://www.catracking.com/sub/p1.htm>. See Geoffrey Lomax, Paul English, and Eric Roberts, *A Breath of Fresh Air*, The AMERICAN PROSPECT ONLINE, September 18, 2005.

<sup>13</sup> S.B. 1446 (Escutia, 2004) would require the establishment, pursuant to the agreement, of the Interagency Office of Environmental Health Tracking within the Division of Environmental and Occupational Disease Control within the State Department of Health Services for the purpose of implementing the health tracking program. The bill has not yet passed.

<sup>14</sup> Fla. Stat. § 381.006 (2005).

<sup>15</sup> La. R.S. 40:1300.171 (2005).

<sup>16</sup> Montana H.B. 582 (2001) required the Montana Department of Public Health and Human Services (DPHHS) to conduct a feasibility study on the development of a chronic disease registry.

regulatory powers, and occupational health and safety protections, among others. The sheer volume of these legal materials prohibited us from conducting a comprehensive survey of these provisions in every state. However, we have examined a sufficiently large sample of state statutes and regulations to assess the variations in how states approach these issues and to draw meaningful conclusions from these approaches.

**Statutes or regulations that facilitate the acquisition of data.** States have adopted varying approaches to facilitate the acquisition of data by government agencies. State statutes and regulations may grant surveillance powers that authorize the collection of health and environmental data by government agencies. To facilitate these surveillance activities, states may require individuals or entities to retain certain types of information and to make this information available at the request of the state. Alternatively, state laws may require individuals or entities to affirmatively report specified data to the relevant state agencies, often pursuant to a specific procedure and within a legally-prescribed time frame. Finally, laws may allow agencies to access existing databases containing relevant information.

The creation of a functional EPHT program hinges on the availability of three categories of data: environmental hazard data, environmental exposure data, and public health data. Typically, a single state agency is not authorized to acquire all three types of data. As a consequence, EPHT may necessitate sharing data gathered through the existing surveillance powers of public health agencies, environmental health agencies, occupational health agencies, and departments of labor.

*Acquisition of environmental hazard data.* In general, states have empowered a specialized environmental agency with authority to track and regulate environmental hazards, such as air pollution, water pollution, and waste disposal. Specific tracking efforts may be in place for metals, persistent organic pollutants, and pesticides. Environmental agencies may acquire data on environmental hazards through mandatory or voluntary reporting by regulated industries, surveillance activities conducted by the agency itself, or via the aggregation of information from other sources such as local governments or non-governmental entities.

The most prevalent system of monitoring air and water pollution is through direct regulation of facilities that emit contaminants or pollutants. All states regulate facilities that emit environmentally hazardous substances, and many states require the owners or operators of any facility that emits contaminants to regularly test, monitor, and report emission results. Regulated facilities include those that contribute to air pollution<sup>17</sup> and water pollution,<sup>18</sup> as well as those that transport and store hazardous and/or solid waste. Beyond measuring the actual emissions, some states, particularly for waste storage facilities, require the facility to regularly test for contamination in the surrounding

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<sup>17</sup> For example, Missouri requires persons engaged in operations that contribute to air pollution to monitor emissions and file results with the state. VAMS § 643.050.

<sup>18</sup> New Jersey has similar requirements for entities that regularly discharge contaminants into state waterways. NJSA 58:10A-6.

areas.<sup>19</sup> In order to substantiate compliance with monitoring requirements, many states authorize state employees to enter premises to inspect records and collect samples for independent verification.<sup>20</sup>

Another common approach utilized by states involves authorizing the state agency to collect samples and monitor pollution independently of regulated facilities. Many states, however, do not explicitly allow for the routine collection of samples. Instead the environmental agency is permitted to encourage, conduct, or participate in studies and investigations. Agencies will often utilize this type of authority to conduct investigations into the causes, effects, prevention, and control of environmental hazards such as air and water pollution.<sup>21</sup>

Some states have adopted regional or local approaches to compiling environmental data. This system works both for monitoring air and water pollution. Several states create regional air monitoring districts, based primarily on population.<sup>22</sup> States also create local water monitoring systems, charged with protecting particular water systems (e.g., rivers, lakes, etc.).<sup>23</sup> In some instances, such as with California's State Water Quality Control Board, the monitoring system compiles all water quality monitoring data, from federal, state, and local governments, as well as private, non-profit and citizen groups.<sup>24</sup> The Texas Natural Resources Conservation Commission engages in a similarly expansive role in assessing water quality.<sup>25</sup>

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<sup>19</sup> Solid waste facilities in New Jersey are required to routinely monitor methane production and maintain wells to test groundwater for contamination. NJSA 13:1E-6.

<sup>20</sup> In Colorado, various water conservation districts are authorized to enter private property to collect samples. CRSA § 37-46-107. The New Jersey Department of Environment Protection is similarly authorized to enter any facility to investigate suspected sources of contaminants. NJSA 13:1D-9.

<sup>21</sup> See, e.g., Neb. Rev. St. § 81-1504. The New Jersey Department of Environmental Protection is authorized to conduct research to determine hazards to the environment and its ecology. NJSA 13:1D-9.

<sup>22</sup> California has created Air Pollution Control Districts, which monitor air quality in conjunction with the State Air Resources Board. West's Ann. Cal. Health & Safety Code §§ 39607, 40910.

<sup>23</sup> Florida has specifically created programs to monitor water quality in Lake Okeechobee as well as the Everglades. FSA §§ 373.4592, 373.4595. Separately, the state has required local governments to analyze coastal water quality. FLA § 163.3178. However, to consolidate information, Florida has required the Department of Water Resources to compile and maintain water quality data from local governments, water management districts, and other state agencies. FSA § 373.026.

<sup>24</sup> West's Ann. Cal. Water Code § 13181.

<sup>25</sup> This Commission supervises individual river authorities in the collection of data, and coordinates with other state agencies to monitor agricultural pollution. The Commission reviews "wastewater discharges, nonpoint source pollution, nutrient loading, toxic material, [and] biological health of aquatic life." VTCA Water Code § 26.0135. The Commission is also specifically authorized to accept environmental data from any lab accredited by the Commission. VTCA Water Code § 5.127.

*Acquisition of public health data.* All states authorize the collection of public health data through surveillance and reporting mechanisms. Most states have enacted general public health powers statutes that authorize the state's health department to conduct studies or investigations into public health concerns.<sup>26</sup> Many state statutes and regulations additionally empower agencies to collect data for particular health concerns, creating registries or databases to track the incidence of selected health conditions. A few states have created centralized chronic disease surveillance systems covering multiple conditions,<sup>27</sup> but most have adopted a disease-specific approach to the extent that they collect these data at all. States may collect information on cancer, birth defects, lead poisoning, diabetes, neurodevelopmental outcomes, heart disease, autoimmune disorders, kidney diseases, and neurological diseases, among others.

With a grant of legal authority to affirmatively track health outcomes or syndromes, the impetus is on the state to engage in surveillance and affirmatively acquire the information. Often, other entities that have information sought by the state must make this information available at the state's request. For example, Hawaii,<sup>28</sup> Connecticut,<sup>29</sup> and California,<sup>30</sup> require health care facilities to make data about birth defects available to the state for tracking purposes.

Alternatively, a state may require others (e.g., health care providers or labs) to report all occurrences of certain conditions to the health department. Reporting statutes and regulations may mandate reporting within a specified time frame once a condition or syndrome is detected or may only require periodic reports from providers. States may mandate reporting for chronic conditions, including cancer,<sup>31</sup> respiratory diseases,<sup>32</sup> and lead poisoning,<sup>33</sup> among others.

The vast majority of statutes do not specify the acquisition of particular data; instead the health department determines what data needs to be collected, often through regulations.<sup>34</sup> In some cases, states allow for individuals to opt-out of providing identifiable information to state reporting databases.<sup>35</sup>

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<sup>26</sup> For example, Arizona authorizes its Department of Health to collect all data and information relating to public health in relation to the prevention of disease. ARS § 36-133.

<sup>27</sup> See, e.g., Arizona's statewide chronic disease surveillance system for cancer, birth defects, and other chronic diseases. ARS § 36-133.

<sup>28</sup> HI St § 324-42.

<sup>29</sup> CGSA § 19a-56a.

<sup>30</sup> West's Ann.Cal.Health & Safety Code § 103830.

<sup>31</sup> See, e.g., West's Ann.Cal. Health & Safety § 103885 (requiring doctors to report incidents of cancer in California); ID St § 57-1074 (similar provision in Idaho); KS St § 65-1, 169 (similar provision in Kansas); MCLA § 333.2619 (similar provision in Michigan).

<sup>32</sup> CGSA § 10-206 (Connecticut school boards must annually report incidence of asthma to local health departments).

<sup>33</sup> See, e.g., notes 28-30 *supra*.

<sup>34</sup> The Illinois Chronic Kidney Disease program requires healthcare providers to collect data, but allows the department of public health to establish procedures to compile the data. 20 ILCS

*Acquisition of environmental exposure data.* Environmental exposure data may provide the link between environmental hazards and public health outcomes. State statutes and regulations infrequently authorize the collection of environmental exposure data under public health or environmental surveillance powers, although some such data collection may be permitted or even required under occupational health and safety codes. The most widespread type of environmental exposure monitoring by states has been related to the detection of elevated blood lead levels. Many states require reporting of elevated blood lead levels, particularly in children, to the state health department. Additionally, in some cases state laws authorize the department to engage in follow-up environmental assessment and abatement activities targeted at reducing lead exposure.<sup>36</sup> Biomonitoring for other types of environmental exposures, while potentially useful for EPHT, is rarely explicitly authorized under state law and may require additional legal authority.<sup>37</sup>

**Statutes or regulations that allow or restrict the use of data for EPHT.** Once data has been acquired by the state, how may this data be used and when may it be disclosed? While EPHT necessitates the analysis of data concerning environmental hazards, environmental exposures, and public health outcomes, the agencies with access to these data may not be allowed to share them or release them. Some states explicitly allow information sharing between agencies, but many others do not address this issue. Moreover, some types of information are explicitly prohibited from disclosure outside of the agency that collected it.

Ultimately, whether data may be used, shared, or disclosed for EPHT purposes will depend on the acceptability of these practices under the law, and frequently will be determined by the following factors: 1) whether the applicable law authorizes, explicitly or implicitly, the proposed use of the data; 2) whether the data is identifiable or not (in the case of public health data); 3) whom the data is being used by, shared with, or disclosed to (and whether this individual, entity, or group is within or outside the agency that has possession of the data); and 4) whether legal provisions restrict certain types of use or disclosure of the data (e.g., privacy, confidentiality, or proprietary protections).

*Use of environmental hazard data for EPHT.* Under many state legal frameworks, environmental hazard data can be used for multiple purposes including EPHT. The vast majority of states indicate that the environmental hazard data collected by environmental agencies should be generally available to the public. These data are often aggregated and

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2310/2310-339. For renal diseases, Illinois only requires the individual's name and treatment received. ILCS 2310/2310-335.

<sup>35</sup> For example, Minnesota allows parents to opt out of identifying information regarding birth defects, although information about the birth defect can still be collected. MSA §144.2216.

<sup>36</sup> See, e.g., Ann.Cal.Health & Safety Code § 124125; Ga. Code Ann., § 31-41-11.

<sup>37</sup> The California legislature has a pending bill to enact a comprehensive biomonitoring system. S.B. 1168 (Ortiz, 2004).

made available to the public through centralized databases maintained by the state.<sup>38</sup> Some state laws place limits on the disclosure of environmental hazard data to protect the confidentiality of alleged trade secrets or other proprietary information.<sup>39</sup> Confidentiality protection of this sort may be absolute, or may be subject to exceptions. For example, data relating to trade secrets compiled by the Texas Natural Resources Conservation Commission can be shared with other state agencies or the federal government, provided that the agency requesting the information takes precautions to protect the trade secrets.<sup>40</sup>

*Use of public health data for EPHT.* Under the laws of many states, public health data may be used for subsequent public health purposes and may even be disclosed outside the agency in order to achieve these purposes. However, legal restrictions may limit the use and disclosure of some public health data, and therefore may impede EPHT activities.

Privacy laws vary greatly among jurisdictions. Privacy protections for health information may vary according to the type of information, how it was collected, who possesses it, and what it is being used for at a particular time. Federal and state laws establish privacy protections for health data. The federal HIPAA Privacy Rule governs the disclosure of some identifiable health information by covered entities such as health care providers, hospitals, and health information clearinghouses.<sup>41</sup> The Privacy Rule explicitly permits sharing of identifiable information for public health purposes.<sup>42</sup> The Privacy Rule does not preempt federal, state, local, or tribal statutes that require or permit disclosure of identifiable information for a specific public health purpose, including those that grant heightened privacy protection above the national standards.<sup>43</sup>

All states provide some level of privacy protection for identifiable health data in the possession of the public health agency. Most state laws additionally permit disclosure of identifiable public health data in the possession of state and local public health departments for specific purposes (e.g., epidemiological investigations, partner

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<sup>38</sup> For example, Illinois requires that data regarding hazardous waste sites, including use, handling, storage and disposal be available to the public (415 ILCS 5/20.1); Florida requires that its central repository of water pollution data make its information public (FSA § 373.026); and Michigan requires compliance monitoring reports for air pollution to be available to the public (MCLA 324.5516).

<sup>39</sup> In Nebraska, data collected regarding air, land and water pollution are confidential if related to a trade secret. Neb. Rev. Stat. § 81-1504. Michigan explicitly makes confidential all data collected by the Director of Pollution Control with regards to restricted pesticides. MCLA § 324.8712

<sup>40</sup> VCTA Water Code § 5.175.

<sup>41</sup> Pub. Law 1104-191. HIPAA was passed in 1996 by Congress. The final version of the Privacy Rule was adopted by the Department of Health and Human Services in 2002. *See also*, Centers for Disease Control and Prevention, HIPAA Privacy Rule and Public Health: Guidance from the CDC and the U.S. Department of Health and Human Services, 52 (S-1) MMWR 1 (2003) [“CDC HIPAA Guidance”].

<sup>42</sup> *See* 45 CFR § 164.512(b) (2002); CDC HIPAA Guidance, at 2, 5, 8.

<sup>43</sup> *See* 45 CFR § 160.203 (a) (2002); CDC HIPAA Guidance, at 10-11.

notification, court proceedings).<sup>44</sup> The level of privacy protection afforded to health data in the possession of public health agencies in their respective jurisdictions also varies according to the type of public health data being collected or used. Some states have opted for generally applicable privacy protections, while others have granted exceptional privacy protection to certain disease-specific information, such as information related to genetics<sup>45</sup> or HIV status.<sup>46</sup> When state legal provisions expressly prevent the health agency from sharing identifiable data with any outside group,<sup>47</sup> it may be unclear whether this prohibition on disclosure includes other agencies in the government or only non-governmental agencies. Some states restrict data use to studies consistent with the goals of the statute authorizing the collection of the data<sup>48</sup> or for legitimate scientific research.<sup>49</sup>

Another strategy used to keep personal information confidential is to require the health department to obtain consent from the patient or their representative before sharing personal information about them. Consent may be required for the collection of data, for subsequent uses of the data (e.g., epidemiology, research), or both.<sup>50</sup> However, some states have provided for exceptions to consent requirements if the public health use of the data is approved by an independent review board.<sup>51</sup>

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<sup>44</sup> Lawrence O. Gostin, Zita Lazzarini, Vera S. Neslund, Michael T. Osterholm, *The public health information infrastructure. A national review of the law on health information privacy*, 275(24) JAMA 1921 (1996).

<sup>45</sup> See Lawrence O. Gostin & James G. Hodge, Jr., *Genetic Privacy and the Law: An End to Genetics Exceptionalism*, 40 JURIMETRICS J. 21 (1999).

<sup>46</sup> See Scott Burris, *Public Health, "AIDS Exceptionalism" and the Law*, 27 MARSHALL L. REV. 251, 272 (1994); NAMES DEBATE, *supra* note 15, at 736-42 (1998). See also, Ronald Bayer, *Public Health Policy and the AIDS Epidemic: An End to HIV Exceptionalism?*, 324 NEW ENG. J. MED. 1500, 1501 (1991).

<sup>47</sup> For example, the personal data collected in the Hawaii birth defect program is considered confidential. HI St § 321-423. Non-identifying data, however can be used for research purposes. HI St. §324-43. A similar, though less explicit, approach was taken in South Carolina's Alzheimer's Disease Registry: only non-identifying data can be shared for research purposes. SC Code 1976 § 44-36-10.

<sup>48</sup> For example, information from the Connecticut Birth Defects Surveillance Program can only be used for the purposes of the program. CGSA §§ 19a-56a.

<sup>49</sup> The Hawaii birth defects program allows non-identifying data collected to be used by the Department of Health or other researchers only to advance public health. HI St § 324-43. Likewise, the data collected in regional cancer registries in California can only be shared with researchers performing demographic, epidemiological, or similar studies. West's Ann.Cal. Health & Safety Code § 103885. Kansas, on the other hand allows non-identifying information from its diabetes database to be released to organizations or scholarly investigators. KS St § 65-1,116.

<sup>50</sup> For example, in Minnesota, parents of babies with birth defects are first given the option of preventing the health department from collecting identifying information. For those parents that choose to have identifying information collected, the department cannot share that information except to qualified researchers, and then only with the consent of the parents. MSA §§ 144.2216-19.

<sup>51</sup> See, e.g., Hawaii, where the cancer commission can approve revealing otherwise confidential information to researchers. HI St § 321-43.

#### IV. Montana's Legal Infrastructure and EPHT: A Preliminary Assessment

Montana's statutes and regulations provide some of the legal tools necessary to develop and implement an EPHT program. However, our assessment of Montana law suggests that the legal provisions needed to acquire, share, analyze, and disclose relevant data for EPHT are disjointed, ambiguous, and in some cases, inadequate for the task. The ability of Montana to implement EPHT will hinge on two areas of legal authority: 1) authorization to acquire necessary data to conduct EPHT, and 2) authorization to allow these data to be utilized, shared, or disclosed to achieve the analytical and practical goals of EPHT.

**Authorization to acquire EPHT data under Montana law.** Montana law provides significant authority to acquire environmental hazard data and public health data. State statutes and regulations provide more limited authority for the acquisition of environmental exposure data.

*Acquiring environmental hazard data under Montana law.* The Montana Environmental Policy Act (MEPA)<sup>52</sup> and related environmental statutes govern the acquisition and use of environmental hazard data in Montana.<sup>53</sup> MEPA authorizes the Department of Environmental Quality (DEQ) to primarily oversee environmental regulation and establishes the Board of Environmental Review (BER) within DEQ to address specific regulatory functions.<sup>54</sup>

DEQ does not possess general data collection authority. Rather, the department is granted the authorization to collect data for designated categories of environmental hazards, including air pollution (emissions and ambient air quality),<sup>55</sup> water quality,<sup>56</sup>

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<sup>52</sup> MCA § 75-1-101 et seq.

<sup>53</sup> See generally, MCA, Title 75. The Environmental Quality Council (EQC), the legislative oversight body charged with overseeing MEPA, has general duties that include gathering "timely and authoritative evidence" regarding the quality of the environment. MCA § 5-16-104; MCA § 75-1-324 (1). The EQC has broad record gathering, surveillance, and investigatory powers linked to environmental quality assessment, including powers to conduct investigations and studies related to environmental quality and to examine all records held by any other institution of the state of Montana. MCA § 75-1-324 (4); MCA § 75-1-211.

<sup>54</sup> MCA § 75-1-101.

<sup>55</sup> DEQ is responsible to "determine, by means of field studies and sampling, the degree of air contaminants and air pollution in the state" and "collect and disseminate information...relating to air contamination and air pollution." MCA §§ 75-2-112 (2)(g), (i). DEQ can also determine regulations for monitoring, reporting, and recordkeeping of machines, equipment, or facilities that contribute to air pollution, and requirements and procedures for submittal of information necessary to determine the location, quantity, and type of emissions; requirements for inspection, monitoring, recordkeeping, compliance certification, and reporting; and procedures for tracking activities conducted under general permits. MCA § 75-2-211; MCA §§ 75-2-217(b), (e), (o).

<sup>56</sup> DEQ has a duty to collect data relating to the control of water pollution (including encouragement of studies). MCA § 75-5-212 (1). Specifically, DEQ is required to have waters

waste management,<sup>57</sup> and indoor air pollution (asbestos<sup>58</sup> and radon<sup>59</sup>). Since the legal authority to collect data is distinct for each type of environmental hazard, any effort to expand data collection to track new environmental hazards would require modifications to statutory and regulatory provisions.

Additionally, the Montana Department of Agriculture (DOA) retains authority to collect and analyze environmental samples pursuant to its regulation of pesticides.<sup>60</sup>

*Acquiring public health data under Montana law.* The MT Code grants general public health authority to the Montana Department of Public Health and Human Services (DPHHS). DPHHS has broad surveillance powers to engage in “investigations” regarding the “control of diseases and the improvement of public health.”<sup>61</sup> The MT Code also allows public health officials to request health information from public officials and corporations.<sup>62</sup> However, the relevant statutory and regulatory provisions do not specifically outline the types of health data collection permitted or from which exact sources data can be obtained. While surveillance and reporting of environmentally-related health conditions could potentially be justified under these broad powers, virtually all of the statutory and regulatory public health reporting requirements pertain to communicable diseases caused by infectious agents.<sup>63</sup> Lead poisoning is the only environmental condition currently reportable under the ARM.<sup>64</sup> The only chronic disease registry established under Montana law is the tumor registry. Healthcare practitioners, laboratories, and hospitals are required to report medical and personal information to DPHHS with regards to certain cancerous tumors.<sup>65</sup> Health information about persons with developmental disabilities that may be relevant to EPHT may also be acquired by DPHHS through its development disabilities program.<sup>66</sup>

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examined to determine any possible threats to public health. MCA § 75-6-104. DEQ can also require certain landfill operators to monitor groundwater for contamination. MCA § 75-10-207.

<sup>57</sup> In the area of waste management, DEQ bears much of the burden of tracking and monitoring environmental effects. Notably, with regards to hazardous waste (which includes any waste that may “pose a substantial present or potential hazard to human health or the environment”), DEQ may require that owners of facilities that create or process hazardous waste collect and analyze samples, and report the data to DEQ. MCA §§ 75-10-403, 75-10-405 (1)(f). DEQ can conduct its own studies and research, and is allowed to enter property to collect samples or inspect records. MCA §§ 75-10-404(1)(b) & (c), 75-10-410. DEQ also must require operators of underground tanks perform tests to determine if there is a public or environmental health hazard. The operators must maintain and report results. MCA § 75-11-509.

<sup>58</sup> DEQ can establish regulations for projects involving asbestos, and can enter property to collect samples relating to asbestos projects. MCA §§ 15-2-502, 75-2-518.

<sup>59</sup> For radon contamination, individuals may report testing results to DEQ. MCA § 75-3-604 (1).

<sup>60</sup> MCA § 80-8-304.

<sup>61</sup> MCA § 50-1-202 (2).

<sup>62</sup> MCA § 50-16-101.

<sup>63</sup> MCA §§ 50-16; 50-2-118; 50-18; 50-17; ARM 37.114.501 et seq.

<sup>64</sup> ARM 37.114.546.

<sup>65</sup> MCA § 50-15-703; ARM 37.8.1801 et seq.

<sup>66</sup> MCA § 53-20-101 et seq.; ARM 37.34.101 et seq.

In the occupational health setting, physicians, hospital and clinic personnel, and state employees are required to report occupational diseases to the Department of Labor and Industry (DLI) within 10 days of discovery.<sup>67</sup> Occupational diseases include health conditions caused by exposure to a substance or industrial practice that is hazardous to health and has symptoms of an industrial disease that is known to have resulted from the same type of exposure in other cases.<sup>68</sup> Reporting requirements do not mandate the inclusion of environmental exposure data. DLI may also conduct inspections to assess compliance with occupational health standards and share relevant information with DEQ, but not DPHHS.<sup>69</sup> These powers only apply to diseases that arise from a person's employment.

A more explicit delineation of surveillance and reporting activities than currently exists under Montana law could enhance the state's ability to engage in EPHT. Furthermore, listing with specificity the desired public health syndromes and conditions to be tracked by an EPHT system would facilitate the collection of data within such a system. For example, since local health authorities are required to "investigate and take whatever steps are necessary" to prevent the spread of any reportable disease,<sup>70</sup> the list of reportable diseases could be expanded to include health conditions relevant to EPHT.

*Acquiring environmental exposure data under Montana law.* Montana's laws do not directly address the collection of environmental exposure data. Arguably, existing public health powers could allow for the collection of environmental exposure data by DPHHS. Regardless, it would help to have an explicit statutory provision authorizing this type of data collection or reporting.

*Use of environmental hazard data for EPHT under Montana law.* Data collected by DEQ are generally publicly available. However, if the entity whose environmental hazard data has been acquired certifies that these data constitute trade secrets, the information will be kept confidential and may only be used by DEQ. Similar provisions regarding data confidentiality apply to data related to air pollution<sup>71</sup> and water quality.<sup>72</sup> Radon data collected from non-public structures is considered confidential unless it is being used for authorized scientific research.<sup>73</sup> These restrictions on the uses of environmental hazard data are relatively minor, but the trade secret protections could hinder EPHT if they prevented these data from being utilized along with other relevant data.

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<sup>67</sup> MCA § 50-70-107.

<sup>68</sup> MCA § 50-70-103(4).

<sup>69</sup> MCA § 50-70-115.

<sup>70</sup> ARM § 37.114.314.

<sup>71</sup> MCA § 75-2-105.

<sup>72</sup> MCA § 75-5-105.

<sup>73</sup> MCA § 75-3-604 (2).

*Use of public health data for EPHT under Montana law.* In general, health data held by DPHHS can be released only under certain circumstances outlined in the MT Code.<sup>74</sup> Importantly, data can be disclosed to another state or local public health agency for purposes of preventing injury from disease.<sup>75</sup> Nevertheless, it is doubtful that this exception could be interpreted broadly enough to justify sharing public health data for EPHT purposes with other state agencies in Montana outside of DPHHS. Data collected by the state tumor registry is confidential by default. However, data in the registry may be released to a person or organization qualified to perform data processing or data analysis, provided the person or organization has safeguards against unauthorized disclosure.<sup>76</sup> Developmental disability data held by DPHHS also is subject to strong confidentiality protections.<sup>77</sup> It may be preferable to have a specific section of the Montana Code that directly authorizes public health tracking for environmental health conditions and explicitly legitimizes the use and release of these data for purposes of EPHT.

*Use of environmental exposure data for EPHT under Montana law.* As mentioned above, it is unclear from legal authorities whether environmental exposure data can be collected in Montana by the state. The use of these data in EPHT efforts is therefore similarly unresolved. Statutes and regulations that permit EPHT should be sure to include the power to use these data accordingly given their importance to EPHT.

*Sharing of data between state agencies.* The legal infrastructure in Montana does not clearly allow for the sharing of information between agencies for purposes of EPHT, and does not provide for extensive collaboration between DPHHS and DEQ. Coordinated activities between the agencies are rarely authorized in the MT Code and ARM.<sup>78</sup> A modified legal regime could explicitly permit coordinated activities for EPHT.

## **V. Recommendations and Options for Implementing EPHT in Montana**

**Recommendation 1: Reform the legal framework in Montana to facilitate the implementation of EPHT.** As described above, Montana's statutory and regulatory structure, as currently configured, is not conducive to the development and implementation of a comprehensive EPHT system. Possible legal reforms to consider include:

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<sup>74</sup> MCA § 50-16-603. The Uniform Health Care Information Act also may apply to some health data held by DPHHS, but it is unclear how this act applies or where it may be found in the MT Code. MCA § 50-16-606.

<sup>75</sup> MCA § 50-16-503 (3), (5), (7).

<sup>76</sup> MCA § 50-15-704.

<sup>77</sup> MCA § 53-20-161; ARM 37.34.108.

<sup>78</sup> DPHHS licenses laboratories that assess the quality of public water supplies. When these labs find contaminants in excess of state requirements, they are obligated to report to DEQ. ARM 37.12.341. The Department of Labor and Industry shall report occupational health hazards to the DEQ and cooperate with the DEQ. MCA § 50-71-109.

- Augmentation of data collection powers related to environmental hazards, environmental exposures, and public health data;
- Explicit statutory authorization for EPHT;
- Unambiguous legal authority to share all relevant data to conduct EPHT activities;
- Reassessment of privacy and proprietary protections on information to appropriately balance these protections with the need to access relevant data for EPHT purposes;
- Designation of a centralized government agency responsible for coordinating EPHT efforts (see Recommendation 2); and
- Linkage of EPHT with other core public health powers.

Legal reform along these lines could take place as a component of a comprehensive law reform effort such as the Montana public health law modernization effort, or alternatively, could be accomplished through partial modification of existing laws.

**Recommendation 2: Designate a centralized agency to engage in EPHT activities on behalf of the state government.** The current disjointed powers and responsibilities between DPHHS, DEQ, and other state agencies, and the lack of clear authority to share information between these agencies may hinder efforts to achieve the goals of an EPHT system. A new division within DPHHS could be created to explicitly manage the EPHT program and interface with other state agencies and non-governmental entities that have relevant expertise. This approach would likely require additional legal authorization to acquire or share information between DPHHS, DEQ, other state agencies, and non-governmental entities.

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Please note that the findings and recommendations stated above are based solely on a review of statutory and administrative public health and environmental laws in Montana and other states, as well as the authors' additional knowledge of the Montana public health and environmental protection systems. We acknowledge that other factors underlie whether to proceed with statutory proposals in furtherance of these recommendations, including political factors and how public health is actually practiced in the state regardless of specific laws. We plan to work in collaboration with Montana DPHHS to refine these analyses and recommendations. Please let us know if you have any questions, comments, or need clarifications of any of the statements or corresponding research.

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